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IN THE
Supreme Court of the United States
OCTOBER TERM, 1985

MARGARET M. HECKLER, Secretary of Health and Human Services,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF OF AMICI CURIAE THE ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES; NATIONAL DOWN SYNDROME CONGRESS; SPINA BIFIDA ASSOCIATION OF AMERICA and FUND FOR EQUAL ACCESS TO SOCIETY IN SUPPORT OF PETITIONER, MARGARET M. HECKLER

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BRIEF OF AMICI CURIAE THE ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES; *et. al.*, IN SUPPORT OF PETITIONER, MARGARET M. HECKLER

INTEREST OF AMICI CURIAE [1]

Amici are organizations of parents of children who are disabled and of disabled adults and others who have been and continue to be directly affected by and actively interested in the enforcement of Section 504 of the Rehabilitation Act of 1973 by Petitioner, Margaret M. Heckler, with respect to the rights afforded to handicapped infant patients under that Act to an equal opportunity to receive the same type of beneficial medical treatment routinely provided to non-handicapped infant patients. The membership of these organizations include large numbers of

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[1] All parties have consented to the filing of this brief.

parents of children with the types of disabilities that have most frequently been the basis of decisions to withhold beneficial medical treatment on the basis of handicap.

The ASSOCIATION FOR RETARDED CITIZENS of the UNITED STATES is the largest voluntary organization in the United States devoted to securing the rights of, and effective services for, the approximately six million retarded citizens. Its national membership numbers over 150,000 people, more than half of whom are parents of retarded children and adults, and includes people who are mentally retarded themselves. ARC/US has chapters in 49 of the 50 states and 1,300 local chapters in cities, counties and towns across the country. Since its founding in 1950, ARC/US has participated actively in the formulation of public policy respecting the rights of and services for retarded citizens and has been recognized in every forum, including the Congress, state legislatures, rulemaking proceedings, and in the courts, as fairly and fully representative of the interests of retarded citizens and their families. ARC/US participated in the congressional formulation and passage of Section 504 of the Rehabilitation Act of 1973 and its amendments.

The NATIONAL DOWN SYNDROME CONGRESS is a voluntary organization of parents and families of people with Down's syndrome. Established as a national organization in 1974, the National Down Syndrome Congress is a network of more than 600 parent groups serving the needs of families in their local communities. Among its official purposes are "[to] address the social policies and conditions that limit the full growth and potential of children and adults with Down Syndrome." Its monthly publication, *Down's Syndrome News*, reaches 50,000 people.

The SPINA BIFIDA ASSOCIATION OF AMERICA was founded in 1972 to foster and promote the human rights of all people having the condition known as spina

bifida (or open spine at birth). Its national membership comprises 10,000 families and professionals. In 1979 the Association adopted a position in favor of the early evaluation and medical/surgical treatment of every infant born with spina bifida.

The FUND FOR EQUAL ACCESS TO SOCIETY is a non-profit corporation founded in 1980 to promote social and economic opportunities for persons with disabilities. During the last five years the Fund has provided assistance to over one hundred Federal, state and local health and education agencies in the planning, development, drafting and implementation of state laws, regulations, interagency agreements and policies designed to carry out the requirements of Section 504 of the Rehabilitation Act of 1973.

SUMMARY OF ARGUMENT

This case presents the narrow question of whether Congress in enacting the broad statutory language of Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of handicap in the operation of programs receiving Federal financial assistance, intended to exclude handicapped infants or children from such protection insofar as the provision of life-sustaining medical treatment is concerned.

A review of the history of the discrimination against children with disabilities that prompted Amici and other national parent organizations to press Congress for the enactment of Section 504 reveals numerous instances of the denial of equal opportunity to beneficial medical treatment and health care to handicapped patients. This inequality in the provision of health care services, thus, was an important part of the overall pattern of bias and discrimination which Congress sought to prohibit through the enactment of the statute. The legislative history surrounding the passage of Section 504 directly supports its applicability to the discriminatory denial of health care

services, as does the clear congressional intent to track Title VI of the Civil Rights Act of 1964 which, for over twenty years, has prohibited, without exception, all types of discrimination in the provision of medical care and treatment. This Court need only determine whether, given the parallel wording of Section 504 and Title VI, there is any textual basis for adopting a radically different interpretation with respect to discrimination on the basis of handicap.

Decisions to withhold beneficial medical treatment from infants have most frequently been made by health care providers on the basis of non-medical, sociological criteria and then suggested to parents in a manner that results in the parents' inability to provide informed consent. These sociological judgments of physicians who discriminate have been presented variously to parents as medical judgments or as no-treatment recommendations or alternatives despite the fact that often no good faith question exists as to the proper course of medical treatment beneficial to the life and health of the infant. Physicians have frequently denied parents crucially important information regarding the medical condition and developmental capabilities of their children and have often required parents to hurriedly acquiesce in no-treatment "recommendations" during a period of psychological crisis. Thus, the consent provided by parents presented with such judgments and no-treatment alternatives often lacks the "voluntariness" required by the Common Law. In many situations the actual decision to terminate the life of the handicapped infant patient is made by a physician on the basis of sociological factors. This distortion of the traditional role of the physician in our society—a role based on trust in the implicit assumption that the physician always seeks to act in the best interests of the patient—is precisely the type of discrimination which the civil rights laws are designed to prohibit.

ARGUMENT

I. CONGRESS INTENDED SECTION 504 TO PROHIBIT THE DENIAL TO HANDICAPPED PERSONS OF THE BENEFICIAL MEDICAL TREATMENT ROUTINELY PROVIDED TO NON-HANDICAPPED PERSONS.

In *City of Cleburne, Texas* v. *Cleburne Living Center*, 105 S.Ct. 3249 (1985), Justice Stevens and the Chief Justice (concurring) described a "history of unfair and often grotesque mistreatment" imposed "through prejudice and ignorance" against mentally retarded children and adults. *Id.* at 3262. Justice Marshall, in describing this "regime of state mandated segregation and degradation" specifically referred to the link between this regime and prominent members of the medical profession:

> "Fueled by the rising tide of Social Darwinism, the 'science' of eugenics, and the extreme xenophobia of those years, leading medical authorities and others began to portray the 'feebleminded' as a menace to society and civilization . . . responsible in large degree for many if not all of our social problems." *Id.* at 3266.

In *Cleburne* this Court declined to apply heightened scrutiny to classifications disadvantageous to mentally retarded persons on the ground that legislative responses, including the enactment of Section 504 of the Rehabilitation Act of 1973, belie "a continuing antipathy or prejudice" toward mentally retarded persons. *Id.* at 3256. In this case, the question before this Court is whether this same statute forbids the denial to handicapped infants by Federally supported health care providers of critical medical care and treatment which would routinely be provided to non-handicapped infants without consideration of sociological projections or judgments.

A. Physicians Treat Parents of Infants with Life-Threatening Conditions Differently Depending on Whether the Infant Is or Is Not Handicapped.

In the normal course of medical practice, it is usually the physician and not the patient (or parents of the patient) who frames and requests treatment decisions.[2] The experience of Amici, as parents of handicapped children, has been that some physicians act differently towards parents who have infants with identical medical problems based on whether or not the infant is expected to be a handicapped child and adult. Often the very framing of a parental treatment/no-treatment decision by a physician reveals an underlying difference in assumptions regarding the value of the life of the handicapped infant. If a parent takes a sick, non-handicapped child to a hospital for an examination which reveals that the child has a life-threatening infection easily and safely cured by an injection of antibiotics, would any physician seriously ask the parent the question of whether the vitally needed medical treatment should be withheld? Physicians, however, frequently call upon parents of sick, handicapped infants to make such decisions. Parents of infants with spina bifida have been asked to consent to the withholding of antibiotics from their handicapped children with life-threatening infections.[3] In this situation, the physician

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[2] This case concerns the denial of medical assistance to a child who, if given medical assistance, will live and will have a life-long disability. It does *not* raise any questions concerning the withholding of medical assistance which would only prolong dying. Those persons covered by the statute at issue here include both handicapped children who require routine, life-saving surgery to correct a common, unrelated health problem (e.g., the blockage of an esophagus or a heart condition of a Down's syndrome child) and children whose handicapping condition (e.g., spina bifida) could directly contribute to their death if routine surgery or medical treatment (e.g., antibiotics) is withheld or unduly postponed.

[3] Physicians have withheld antibiotics from now deceased infants with spina bifida on the basis of sociological criteria unrelated to their medical condition. Gross, et al., *Early Management and*

suggests to parents a decision which assumes that the withdrawal of a routine medical procedure needed to preserve the life of a handicapped child is acceptable, despite the fact that such a decision would never even be suggested if an infant with the same infection were not handicapped. The *a priori* assumption of such a question is not that the child cannot or will not live, but rather that because of his or her handicap the infant's life has such diminished value that the child *should* not live.

This difference in the treatment of handicapped and non-handicapped children directly reflects the physician's judgment that the life of the handicapped infant is of significantly less value than is the life of the non-handicapped infant. Perhaps the bias and devaluation inherent in seriously presenting the no-treatment option would be clearer if the decision were based on race or sex (other permanent physical characteristics). If physicians in a neonatal intensive care unit, in cases where clearly beneficial treatment was safely available, routinely and seriously presented the no-treatment alternative to parents of black infants but not to parents of white infants, would there be any question of inherent and unlawful bias? Would it suffice to argue that, because of a higher incidence of poverty among black families, such a differentiation in the presentation of treatment alternatives was justified either because of the potential economic burden of another child on the family or because the quality of the child's future life, as measured from the physician's sociological viewpoint, might well be significantly lower because of the child's race? The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research points out "that it is all too easy to undervalue the lives of handicapped infants" [4] and criticizes the presentation of the no-treatment

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Decision-Making for the Treatment of Myelomeningocele 72 Pediatrics 450, 452, 453, 456 (1983). *See also* Brief of *Amicus Curiae* Carlton Johnson.

[4] *Foregoing Life Sustaining Treatment,* President's Commission for the Study of Ethical Problems in Medicine and Biomedical and

alternative by physicians where clearly beneficial treatment is available:

> . . . parents should be able to choose among alternative treatments with similarly beneficial results and among providers, but not to reject treatment that is reliably expected to benefit a seriously ill newborn substantially, as is usually true if life can be saved.[5]

The President's Commission goes on to urge that handicapped infants be treated "no less vigorously than older children with similar handicaps would be treated." [6]

Not all medical decisions to withhold treatment from a handicapped infant are based on different assumptions regarding the value of the infant's life. The pivotal question to be answered is, "If the child were not thought to be permanently disabled, would there be any hesitation in providing a particular type of treatment?" If the answer is "yes" (i.e., there would be a major question about providing the treatment under consideration even if a child were not thought to be permanently handicapped), then the treatment decision would be properly predicated on medical factors related to the infant's current physical condition rather than the infant's status as a handicapped child. However, if the answer is "no" (i.e., the issue of whether to go ahead with treatment is decided ultimately on the basis of an assumption regarding the "quality" of an infant's life after successful treatment), then the decision would appear clearly predicated upon the diminished value assigned to the life of that child. Thus a physician may legitimately decide not to recommend heart surgery

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Behavioral Research, U.S. Government Printing Office 219 (1983). For a description of a similar physician devaluation of life on the basis of race which led to the now infamous Tuskeegee syphilis study *see S.R. No. 93-381: Report to Accompany HR 7724 (P.L. 93-348)*, August 3, 1973, *reprinted in* 1974 U.S. Code Cong. and Ad. News 3642-43, 3652-59.

[5] *Id.* at 217-18.

[6] *Id.* at 219.

for a black child with Down's syndrome because it is medically contraindicated. However, if the physician decides not to recommend clearly beneficial surgery *because* the child is and will be mentally retarded, or *because* the child is and will be black, the basis of the physician's decision has shifted from a medical to a sociological one. There is no more central civil rights issue than a life and death difference in treatment based on a different and lesser valuation of a human life attributable to membership in a particular group.

B. Congress Acted in Light of the Historical Inequality of Medical Care and Treatment to Which Handicapped Children Had Been and Continue to be Subjected.

The passage of Section 504 of the Rehabilitation Act of 1973 [7] represents a deliberate decision by the Congress to correct historical inequities in the provision of medical care and treatment to handicapped children and adults. These historical inequities were often tied to a concept derived from Social Darwinism: that children born with disabilities were "unfit" and, therefore, not "deserving" of the medical care and treatment needed to survive. *Cf. City of Cleburne, Texas* v. *Cleburne Living Center*, 105 S.Ct. 3249, 3266 (1985) (Marshall, J., dissenting). Prior to the enactment of Section 504 numerous incidents in which physicians had withheld clearly beneficial treatment from infants solely on the basis of their handicap had been widely reported.[8] One early example of this type of "medical Darwinism" appeared in a story on the front page of the November 18, 1915 New York Times entitled: "*Defective Babe Dies as Decreed: Physician, Refusing Saving Operation, Defends Course as Wisest for Coun-*

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[7] P.L. 93-112; 29 U.S.C. 794.

[8] *Order Relating to Protective Services, In re Baby Girl Obenauer*, (N.J. Juv. & Dom. Rel. Ct., Morris County, Dec. 22, 1970); Washington Post, October 15, 1971, p. 1 (*re* starvation of a child with Down's syndrome by physicians at Johns Hopkins University Hospital, Baltimore, Maryland); *see also* S. Herr, *Rights and Advocacy for Retarded People*, Chapter 23 (1983).

try's Good." [9] The withholding of beneficial medical treatment was, of course, only one of a wide variety of dehumanizing and destructive practices to which handicapped children and adults were routinely subjected.[10] During the early decades of this century, the states actively enlisted the assistance of physicians and other health workers in these practices. Physicians, social workers, and other professionals were required by law in some states to report to the government all persons "believed by them to be feeble minded".[11] Other states made it "one of the special duties of every health officer and of every public health nurse to institute proceedings to secure the proper segregation and custody of feeble-minded persons." [12] Those states with no formal reporting or registration requirement at least officially encouraged health care professionals to identify disabled children who were to be removed from the family and placed into an institution if their parents "either neglect[ed] or refuse[d] to do so." [13]

During the last decade, many physicians charged with the care and best interests of handicapped newborn infants have continued actively and openly to advocate the application of non-medical criteria to infants in order to justify withdrawing needed and clearly beneficial medical treatment. For example, a 1977 national survey of

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[9] New York Times, November 18, 1915, p. 1.

[10] *Cleburne*, 105 S.Ct. at 3266 (concurring opinion); *see also* on history of proposals to extinguish the mentally retarded as a group; *see also* S. Herr, *supra* note 8 at 23. The legislative history of Section 504 (and its related enactments) and the historical background against which Section 504 was enacted is more fully addressed in the Brief of *Amici Curiae* American Coalition of Citizens with Disabilities, *et al.*

[11] 1931 S.D. Sess. Laws 200, ch. 153, § 3(b), (c); *see also* 1917 Or. Laws 739, 740, ch. 354, §§ 1, 5.

[12] 1918 Ky. Acts 171, ch. 54, § 30; *accord*, 1919 Tenn. Pub. Acts 561, ch. 150, § 5.

[13] 1920 Miss. Laws 294, ch. 210, § 17; 1919 Tenn. Pub. Acts 564, ch. 150, § 4.

pediatricians and pediatric surgeons reported that "potential quality-of-life" was the most important criterion and "possible adverse effects to the family", the second most important criterion used to justify such decisions.[14] While much of this discussion has been couched in both "ethical" and "scientific" terminology, it has often revealed an underlying hostility toward the handicapped infant patient. One recent article by the former head of the Department of General Surgery of the Cleveland Clinic stated that "no child with Down's syndrome ever grew up to be self-sustaining" and suggested that "if the parents still want to rear their child, that should be their decision, but there should be no support from the community or the State." [15] A 1983 editorial in a prominent medical publication stated that "with luck" a Down's syndrome child with esophogeal or duodenal blockage (like Bloomington's Infant Doe) "can be trained to the point of being a happy family pet." [16] Numerous articles appearing in prominent medical publications openly advocate the withdrawal of beneficial medical treatment from handicapped infants on the basis of a wide variety of non-medical criteria, all linked directly to the presence (or anticipated presence) of a permanent handicap.[17]

Most of these articles have invariably sought to justify the withholding of clearly beneficial medical treatment

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[14] Shaw, Randolph & Maynard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 Pediatrics 588 (1977).

[15] Dr. George Crile, *The Right to Life*, Medical Tribune December 19, 1984.

[16] Ravitch, *Big Brother Comes to the Nursery*, Surgical Rounds June 1983 at 10.

[17] *See* Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 New Eng. J. Med. 890 (1973); Angell, *Handicapped Children: Baby Doe and Uncle Sam*, 309 New Eng. J. Med. 659, 660 (1983); Todres, Krans, Howell & Shannon, *Pediatricians Attitudes Affecting Decision-Making in Defective Newborns*, 60 Pediatrics 197, 198 (1977); Affleck, *Physicians' Attitudes Toward Discretionary Medical Treatment of Down's Syndrome Infants*, 18 Mental Retardation 79-81 (1980).

from handicapped infant patients on the basis of either or both of the following non-medical rationales: (1) on a cost/benefit basis society would be better off without the infant, or (2) the burdens which the infant would impose on the family are greater than any benefits to be derived. The value-to-society rationale is predicated on the assumption that only those handicapped infants who are fittest in terms of productivity and economic contribution should live. Those relying on this rationale consistently underestimate the developmental potential and employability of handicapped persons and ignore the substantial and valuable personal and economic contributions of handicapped children and adults to their families and communities.[18]

The second rationale attempts to assess the benefits and burdens of an infant's life on the infant's family. A 1980 summary of four recent surveys of physician attitudes reported that physicians primarily justified no-treatment preferences on the basis of social criteria that particularly relate to the potential for family acceptance and the integration of the child.[19] Not only does the burden-on-the-family rationale confuse the interests of the infant with the interests of the parents, it is also based on the assumption that, in general, parents, siblings, families and communities cannot cope with or adequately support the existence of a handicapped child. Most importantly, this rationale ignores the capacity of family members to grow and to love, ignores the fact that the emotional benefits to the family may well be far more important than any physical demands of caretaking,[20] and overlooks the enormous efforts and accomplishments of parents, so many of whom have unselfishly provided nurturing and support.

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[18] Walker, Feldman, Vohr & Oh, *Cost Benefit Analysis of Neo-Natal Intensive Care for Infants Weighing Less Than 1000 Grams at Birth*, 74 Pediatrics 23 (1984); *see also* Brief of *Amici Curiae* American Association on Mental Deficiency, *et al.*

[19] Affleck, *supra* note 17; *see supra* note 14.

[20] Turnbull & Turnbull, *Parents Speak Out* (2nd ed. 1985).

The National Conference of Catholic Bishops and the American Jewish Congress in a recent Joint Statement rejected both the value-to-society and burden-on-the-family rationales in concluding that an assessment of a child's best interest should not "include the possibility of negative judgments about the value of handicapped children's lives." [21] In sum, both of these rationales represent a serious assault on the traditional medical standard of treatment in the best interests of the patient. This dangerous tendency toward the introduction of sociological factors has been addressed directly by the Canadian Psychiatric Association:

> "We are also uncomfortably aware that it is all too easy to slip into 'doublethink' in this complex area of moral decision making as we exercise our medical responsibility. Our minds can easily move from the goodly desire (held we hope by all physicians) for a rich, full and satisfying life for everyone; to the recognition that, as we perceive their present situation to be, these children may never enjoy such a life; to the latter becoming the reason for our countenancing or even inducing their death. The role of medicine is to help make the quality of life the best possible for all; rather than to cut short the life of humans with various defects—regardless of the degree or type of their deficiency." [22]

C. The Legislative History Surrounding the Enactment of Section 504 Demonstrates that Congress Intended to Broadly Prohibit Unequal Treatment in the Provision of Medical Care and Treatment.

At issue before this Court in the instant case is not whether routine government oversight of medical decision-

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[21] *Principles on Treatment of Handicapped Newborns*, July 25, 1985); *See also Wyatt* v. *Aderholt*, 503 F.2d 1305, 1312 (5th Cir. 1974) with respect to the rejection of a similar argument advanced in connection with the civil commitment of mentally disabled persons.

[22] Beck, *On Withholding Treatment.* A Working Paper for the Professional Standard and Practice Council of the Canadian Psychiatric Association (1975).

making is constitutionally required, but rather whether Congress intended to extend the same civil rights protections applicable to 35 million disabled Americans to a group of infants whose lives are directly at risk because of adverse sociological judgments made by health care providers on the basis of the infant's future status (or assumed future status) as a disabled child and adult. Congress, patterning Section 504 after Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000(d), clearly intended to broadly prohibit discrimination by recipients of Federal funds in all of the activities benefitting from Federal financial assistance.[23]

The legislative history of Title VI demonstrates that Congress clearly intended that there be an "assurance that hospitals financed by Federal money would not deny adequate care to Negroes," 110 Cong. Rec. 1519 (1964) (remarks of Rep. Celler, the prime sponsor of Title VI in the House), and the final regulation implementing Title VI has for over twenty years prohibited discrimination on the basis of race, color or national origin in the operation of health care facilities receiving funds under a wide array of Federal health care programs.[24] Since that time, hospitals have been required to agree to assurances of compliance relating directly to the nonexclusionary treatment of "individuals as . . . patients," [25] and have been prohibited from discrimination on the basis of race, color and national origin both in the selection or determination of eligibility of individuals to receive "health services, and in the provision of such services." [26] Thus, civil rights obligations that bear upon the provision of medical care were at the time of passage of Section 504 neither new nor secret.

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[23] *See Alexander* v. *Choate*, 105 S.Ct. 712, 718 n.13 (1985); *Community Television of Southern California* v. *Gottfried*, 459 U.S. 509 (1983).

[24] 45 C.F.R. 80.

[25] 45 C.F.R. 80.4(d)(2).

[26] 45 C.F.R. 80.5(a); *see also* Brief of Petitioner.

The clear and unrestricted language of the statute and over nine years of experience in applying parallel provisions of Title VI forcefully argue that the intent of Section 504 was to reach the provision of Federally assisted medical care and treatment to handicapped children and adults. A contrary reading would in Judge Winter's words deprive handicapped persons "of a fairly won political victory" and "expose them to the possibility of future decisions excluding other services from Section 504. . . ." *United States* v. *University Hospital, State University of New York at Stony Brook*, 729 F.2d at 162-63 (Winter, J., dissenting).

Along with the plain language of the statute, legislative history supplies the primary guide to the construction of Section 504. As this Court recently observed:

> "Given the lack of debate devoted to § 504 in either the House or Senate when the Rehabilitation Act was passed in 1973, the intent with which Congressman Vanik and Senator Humphrey crafted the predecessor to 504 is a primary signpost on the road toward interpreting the legislative history of § 504." *Alexander* v. *Choate*, 105 S.Ct. at 718 n.13 (1985).

The legislative history surrounding the enactment of Section 504 convincingly demonstrates that Congress was determined to reverse the historical inequities in medical care and treatment which were an important part of that history.

Congressman Vanik, in introducing the original handicap non-discrimination legislation on December 9, 1971,[27] stated "Mr. Speaker, the treatment and regard for the rights of handicapped citizens in our country is one of America's shameful oversights," and immediately singled

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[27] The handicap non-discrimination legislation addressed by both Representative Vanik and Senator Humphrey was subsequently reintroduced by these sponsors and enacted as Section 504. H.R. 14033, 92d Cong., 2d Sess., 118 Cong. Rec. 9712 (1972); S. 3044, 118 Cong. Rec. 525-26 (1972).

out the "100,000 babies [who] are born with defects" annually, among the "masses of the handicapped [who] live and struggle among us, often shunted aside, hidden and ignored. How have we as a nation treated these fellow citizens?" 117 Cong. Rec. at 45974. Noting that much of what happens to handicapped people is "hidden" from the public, behind closed doors, Mr. Vanik described instances of "confinement without treatment," "brutality," and "unexplained deaths," and concluded that, with the enactment of Section 504, Congress would "no longer tolerate the invisibility of the handicapped in America." *Id.* One month later, on the floor of the United States Senate, Senator Humphrey stated that children, youth and adults with mental and physical handicaps "have the right to live" and "to know the dignity to which every human being is entitled." 118 Cong. Rec. 525 (1972). In the view of Senator Humphrey, Section 504 was designed to insure, among other equality guarantees, the "right to health," which he said was "fundamental." *Id.*

Congress was well-aware that physicians and other professional service providers often devalued the lives of handicapped children. Describing the "categories of people who would be directly affected—children who are mentally retarded, physically handicapped"—Senator Humphrey referred to the "disturbing viewpoint that these people are not only forgotten but perhaps expendable." *Id.* Senator Humphrey inserted in the Congressional Record a series of articles which contained stinging criticisms of physicians, psychologists and other professionals who seriously devalued the developmental potential and, indeed, the very lives of handicapped children and which documented the experience of parents who were told by pediatricans that their children's lives would be worthless. 118 Cong. Rec. 9499, 9500. One of these articles documented the experiences of parents who "spoke angrily about pediatricians and purported experts in the field of retardation—the professionals who know pathetically little about the unused potential of retarded children and

who continually discourage and delude parents. . . ." One of these parents stated that "there was so much willingness to eliminate the child, because they did not consider him a productive member of society. . . ." The article went on to conclude that parents share a "deep anger" at a "system which regularly has written off certain categories of handicapped children, their children, as hopeless." 118 Cong. Rec. at 9500.

In fact, Congress intended to allow no children to be "written off" as "hopeless." The legislative history surrounding the passage of Section 504 also demonstrates the express intent of Congress to include not only mildly or moderately disabled persons but also persons with severe disabilities within its coverage. 117 Cong. Rec. 45974 (1971); 118 Cong. Rec. 526 (1972). "[T]he 'expendables,'" as Senator Humphrey described them, 118 Cong. Rec. at 9495, were identified as the primary intended beneficiaries of Section 504. The legislative history also clearly includes infants and children as part of the protected class. Congressman Vanik specifically mentioned "babies . . . born with defects" as part of the group of handicapped persons to be aided by the statute (117 Cong. Rec. at 45974) and Senator Humphrey describes the sweep of the statute as one that addresses "handicapped children, youth and adults who suffer the profound indignity and despair of isolation, discrimination and maltreatment." 118 Cong. Rec. 9497-98.

In sum, when it enacted Section 504, Congress, aware of both the long and well-documented history of discrimination by medical professionals against children and adults with disabilities, clearly intended to prevent such discrimination from continuing in Federally assisted programs. Both the explicit and unrestricted language of the statute and the legislative history surrounding its passage overwhelmingly support the applicability of Section 504 to physicians and health care providers receiving Federal funds who withhold medically indicated treatment from infants solely on the basis of their handicap. If Congress

did not intend that Section 504 be construed in this manner, Congress could most certainly have fashioned an explicit exemption at the time of the enactment or at any time thereafter, including during the consideration last year of complementary provisions contained in the Child Abuse Amendments of 1984.[28]

II. DECISIONS TO WITHHOLD BENEFICIAL MEDICAL TREATMENT FROM INFANTS ON THE BASIS OF THEIR HANDICAP ARE SUGGESTED TO PARENTS BY PHYSICIANS.

A. Physicians Directly Suggest No-Treatment Decisions to Parents of Handicapped Infants.

Decisions to withhold beneficial medical treatment from handicapped infants are, in fact, frequently made by physicians and other health care providers who receive substantial amounts of Federal financial assistance. The tendency of some biased physicians to suggest their own sociological judgments to parents is well documented. The President's Commission reported that some physicians actually make decisions to withhold treatment and others manipulate the situation to ensure that parents will accept their "recommendation." [29] It reported further, that "parents may be excluded from the decisions entirely or presented with a narrower range of choices than is appropriate" and concluded that, as a result of these actions by physicians, "the child loses the protection of its surrogates." [30] If the responsible physician believes that death (i.e., withholding of beneficial treatment) is preferable to life, the physician can and often does present the options to parents in a manner which results in the direct

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[28] *See* Section 127(a) of The Child Abuse Prevention and Treatment Act and Child Abuse Prevention and Treatment and Adoption Reform Act Amendments of 1984 (P.L. 98-457); *see also* Brief of *Amici Curiae* Orrin G. Hatch and Austin J. Murphy.

[29] President's Commission, *supra* note 4 at 210-11.

[30] *Id.* at 211.

imposition of the physician's judgment.[31] Physicians responding to survey questions regarding "acquiescence in parents' decisions" commented that physicians are always either directly involved in forming the decision with the parents or are in a position of directly influencing the decisions parents make through the presentation of the treatment/no-treatment question.[32] During a five year experiment 24 infants with spina bifida were denied life-saving treatment by a team of medical professionals, who, after applying a "quality-of-life" scheme, informed the parents that "we do not consider them obligated to have the baby treated." [33]

In 1981 another prominent neonatologist reported that it might take physicians seeking to instill a "death wish" in parents of handicapped infants as long as three days to succeed in breaking down their resistance.[34] The frequency with which these judgments are likely to be recommended to parents is revealed by a 1977 survey of Massachusetts pediatricians which disclosed that 51% believed that a child with Down's syndrome and duodenal atresia (blockage) should not receive surgery and 67% of the pediatricians would recommend no surgery for a child with severe myelomeningocele (spina bifida).[35] A 1980 summary of four major surveys of physician attitudes reported that social variables are the critical perceived determinants of the preference to withhold treatment.[36]

The role of the physician as described in these studies is hardly that of an independent or neutral fact finder. The

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[31] Duff & Campbell, *supra* note 17; Duff, *Counseling Families and Deciding Care of Severely Defective Children: A Way of Coping with 'Medical Vietnam'*, 167 Pediatrics 315 (1981).

[32] Shaw *et al.*, *supra* note 14 at 590.

[33] Gross *et al.*, *supra* note 3 at 452; *see also* Brief of *Amicus Curiae* Carlton Johnson.

[34] Duff, *supra* note 31 at 315.

[35] Todres, *et al.*, *supra* note 17 at 197-98.

[36] Affleck, *supra* note 17 at 80.

physician is obviously directly involved in the decision-making process and brings to it whatever knowledge, bias or stereotypes he or she possesses. At best, the physician seeks to play the role of a compassionate helper; at worst the physician may seek to impose a "death wish" or gain ratification of a no-treatment decision based on a sociological formula of which the parent is not even aware.

B. The Circumstances Surrounding the Presentation of No-Treatment Decisions Raise Serious Doubts Concerning the Quality of Informed Consent.

Parental consent to (or acquiescence in) a decision to deny beneficial treatment to a handicapped infant (i.e., the simultaneous waiver of a right to treatment and consent to the plan of non-treatment), if it is to be regarded as legally sufficient, must be free of "undue influence." [37] Certainly, the circumstances surrounding the presentation of no-treatment decisions by physicians to parents present a classic opportunity for the exertion of "undue influence." [38] The relationship between the physician and the parents, is one which has as its foundation the theory that the former is learned, skilled and experienced in those subjects about which the latter ordinarily know little or nothing.[39] Despite the vital importance of both the life and health of the child to the parent, the parent must necessarily place great reliance, faith, and confidence in the professional word, advice, and acts of the physician or other health care provider.[40] *Cf. Parham*

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[37] *Ralston* v. *Turpin*, 129 U.S. 663, 670 (1889); *Harding* v. *Handy*, 24 U.S. 11 Wheat. 103, 125 (1826).

[38] *Hummel* v. *State*, 210 Ark. 471, 196 SW 2d 594 (1946); *Adams* v. *Ison*, 248 SW 2d 791 (Ky. 1952); Annot., 50 A.L.R. 3d 918, 920 (1973); *see also* Beck, *supra* note 22 at 7.

[39] *Id.*

[40] *Id.*; *Campbell* v. *Oliva*, 424 F.2d 1244, 1250 (6th Cir. 1970).

v. *J.R.*, 442 U.S. 584, 632 (1979) (Brennan, J., concurring and dissenting) ("even well-meaning parents lack the expertise necessary to evaluate the relative advantages and disadvantages of [medical] treatment").

In light of the basic nature of the physician/patient relationship, the additional presence of one or more factors which occur frequently in the context of no-treatment "recommendations" or "alternatives" presented to parents by physicians strongly suggests that sufficient evidence of "undue influence" may be present to raise serious doubts with respect to the voluntariness of any consent given by the parent. These factors include lack of pertinent information, vulnerability of the parents' mental and emotional state, and the degree to which the physician exerting influence is directly involved in effectuating the resulting decision.[41]

Parents faced with the birth of a child with an unanticipated handicapping condition are rarely provided with accurate information related to both the current medical condition of the infant and the developmental potential and capabilities which can reasonably be predicted. What the parents require is specific, clearly transmitted, honest information about the child, implications for the future and knowledge of what concrete actions they can take to assist the infant's growth and development.[42] Often, in fact, comparatively little medically reliable information is available at or near birth with respect to the future growth and developmental potential of most handicapped infants.[43] The President's Commis-

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[41] *Ralston* v. *Turpin*, *supra* note 37 at 670; *Ostertag* v. *Donovan*, 65 NM 6, 331 P.2d 355 (1958); *Davies* v. *Toms*, 75 S.D. 273, 63 NW 2d 406 (1954); *Verner* v. *Mosely*, 221 Ala. 36, 127 SO 527 (1929); *see also In re Interest of Perry*, 31 Wash. App. 268, 641 P.2d 178 (1982).

[42] Mathbery & Vernick, *Parents of the Mentally Retarded Child: Emotionally Overwhelmed or Informationally Deprived*, 74 J. Pediatrics 953, 954 (1969).

[43] President's Commission, *supra* note 4 at 216, 221 and 228.

sion reports that parents who "are likely to be poorly informed about long-term prospects for the child, be subject to financial exigencies, and be worried about the effects on siblings and the family as a whole receive outdated or incomplete information from their physicians which limits their capacity to act as surrogate decision makers" and describes as a serious shortcoming in current decision-making about seriously ill newborns the fact that "appropriate information may not be communicated to all those involved in the decision." [44] As the Commission notes, when parents are provided information about Down's syndrome and a chance "to hear both points of view," including the availability of excellent adoptive homes, the decision changes.[45]

Studies have revealed that information provided to parents by physicians may be constrained by the physician's judgments or views concerning the social class and race/ethnicity of the infant's family, the perceived emotional stability of the parents, and the physican's lack of accurate information regarding the availability of support services to assist handicapped infants and their parents.[46] The lack of knowledge of pediatricians about handicapping conditions has been both reported to the American Academy of Pediatrics and identified by it as one of the "under-emphasized areas in pediatric residencies" and as a subject "in which education content is inadequate." [47] Indeed, studies have even re-

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[44] *Id.* at 209, 211 and 223.

[45] *Id.* at 223, Testimony of Dr. Norman Fost.

[46] McDonald, Carson, Palmer & Slay, *Physicians Diagnostic Information to Parents of Handicapped Neonates*, 20 Mental Retardation 12, 13 (1982); Kelly & Menalascino, *Physicians' Awareness and Attitudes Toward the Mentally Retarded*, 13 Mental Retardation 10 (1975); Wolraich & Siperstein, *Assessing Professionals' Prognostic Impressions of Mental Retardation*, 21 Mental Retardation 8 (1983).

[47] American Academy of Pediatrics, *Pediatric Education: A Report by the Task Force on Pediatric Education* (1978).

ported that the medical prognosis provided by physicians to parents consistently underestimates the infant's actual chances of survival.[48]

Compounding the lack of information available to parents is the vulnerability of the parents' mental and emotional state. After the birth of a sick and handicapped infant, families are often in "a severe psychological crisis" in which they are foreclosed, as a result of psychological and emotional trauma that generally surrounds the birth of a handicapped infant, from either assimilating properly the information which is provided about the infant's condition or exercising clear and rational judgment concerning a no-treatment decision presented by a physician.[49] In addition, time pressures, often artificial and unnecessary,[50] imposed on parents to consent or acquiesce in the physician's recommendation affect both the capacity of the parents for rational judgment and the quality of the information upon which to base a judgment. This, of course, is the same period of time during which the mother is recuperating from the physical demands of childbirth and may be receiving medication or other medical treatment. The President's Commission has cautioned against "undue haste in decision-making" and observed that "[t]he longer some of the babies survive, the more reliable the prognosis for the infant becomes and the clearer parents and professionals

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[48] Clyman, Sondeman, Ballard & Roth, *What Pediatricians Say to Mothers of Sick Newborns: An Indirect Evaluation of the Counseling Process*, 63 Pediatrics 719 (1979).

[49] Scanlon, *Who Provides Intensive Emotional Care in the NICO*, Professional Nursing (November-December, 1978) at 18; Strong, *The Neonatologist's Duty to Patient and Parents*, 14 Hastings Center Rep. 10, 11 (August 1984); Darling, *Parents, Physicians and Spina Bifida*, 7 Hastings Center Rep. 10, 11 (August 1977); Fost, *Counseling Families Who Have a Child with a Severe Congenital Anomaly*, 67 Pediatrics 32 (1981).

[50] Charney, Weeler & Sutton, *Management of the Newborn with Myelomeningocele: Time for a Decisionmaking Process*, 75 Pediatrics 58-74 (1985).

can be on whether further treatment is warranted or futile." [51] Both research and experience have shown that, after a period of time, parents' attitudes towards the infant they might once have hoped would die may well change, as a relationship of love and affection is allowed to develop.[52] In fact, one medical commentator, concerned that time and the opportunity for bonding it creates may well cause parents to make a "selfish" decision to save the infant's life, actually recommends that parents not be encouraged to nurture their newborn infant.[53]

In sum, because parents often receive biased, incomplete and inadequate information, and are asked to make decisions at a time of psychological and emotional crisis without adequate support, and under time pressures which are often neither necessary nor conducive to informed and reasoned judgment, experience and reality demonstrate a very strong opportunity for the imposition of undue influence by physicians and other health care providers.

The inherent authority and presumed medical/technical knowledge of pediatricians and pediatric surgeons creates a disposition in a significant number of these physicians to exert influence over decisions to withhold medically indicated treatment. In these instances "what passes today for disclosure and consent in physician-patient interactions is largely an unwitting attempt by physicians to shape the disclosure process so that patients will comply with their recommendations" [54] despite the underlying as-

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[51] President's Commission, *supra* note 4 at 216, 221 and 228.

[52] Darling, *supra* note 49. It should also be noted that the parents of Baby Jane Doe, in fact, changed their minds after several months and decided to provide life-sustaining care and treatment.

[53] Pauli & Cassell, *Nurturing a Defective Newborn—Commentary*, 8 Hastings Center Rep. 13, 14 (February 1978).

[54] Katz, *Informed Consent—A Fairy Tale? Law's Vision*, 39 U. Pitt. L. Rev. 137, 142 (1977).

sumption of the physician/patient relationship which is that the physician seeks to prevent illness, to promote healing, to reduce suffering and to save life.[55] As the Canadian Psychiatric Association has observed:

> "Medicine is the healing profession. Medicine is the treating profession. Medicine has earned its honored position not only by appearing to take the patient's side, but by taking the patient's side in point of fact. We have become trusted because we deserve to be trusted. Medicine betrays its identity, and fails in its public trust, when it finds any reason to dicker with death—when it accepts the death of an individual as a means of solving the problems of either the family or of society." [56]

The experience of Amici, as parents of handicapped children (discussed at length on pages 18 through 24 above) demonstrates that the strong preference for non-treatment of handicapped infants held by a significant number of health care providers has in many instances unduly influenced the normal resolve of parents to preserve the health, welfare and physical well-being of their infants and children. In this regard the President's Commission reports that actions have and can be taken to withhold medically indicated treatment from handicapped infants "without the informed approval of parents or surrogates" and observes that "parents may be excluded from the decisions entirely or presented with a narrower range of choices than is appropriate." [57]

As parents of both handicapped children and their non-handicapped brothers and sisters, Amici recognize that our moral and philosophical heritage strongly suggests that a true parent always chooses life for his child and never willingly accepts the loss of a child. This, after all, was the way that King Solomon determined the true

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[55] *See supra* note 22 at 2.

[56] *Id.* at 3.

[57] President's Commission, *supra* note 4 at 209 and 211.

mother between the rival claimants—that the true mother would never countenance the death of her child, no matter how much suffering its continued life would bring to her. It is precisely the ability of some biased physicians to impose sociological judgments on parents which are sharply at odds with traditional concepts of parental caretaking that demonstrates that "undue influence" has seriously impaired the quality of parental consent.[58]

C. The Unreliability of the General Expectation that Parents Will Act in the Best Interests of Their Children Supports the Applicability of Section 504.

This Court in *Parham* v. *J.R.*, 442 U.S. 584 (1978) identified several assumptions that underlie the general expectation that parents will act in the "best interests" of their children: (1) "parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions," (2) parents have "natural bonds of affection" towards their children, and (3) parents, faced with treatment decisions in situations of *bona fide* medical uncertainty, will make such decisions after receiving independent medical advice from physicians as to the course of treatment which will best meet the child's treatment needs.[59] In addition, this Court pointed out that certain other factors, including both a concern that raising questions about the motives underlying parental decisions might seriously disturb the ongoing coherence of the family unit (and by doing so adversely affect the future treatment of the child) and a reliance on the protection afforded by subsequent professional review of the treatment decision,[60] support the need for lessened governmental scrutiny.

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[58] *See* R. Burt, *Refusing Care* in The Handicapped Newborn in American Society (J. Bopp ed. 1986) (in publication). A copy of this document has been placed on file with the Clerk of the Court.

[59] *Parham* v. *J.R.*, 442 U.S. 584, 602, 604, 607-10, 613 (1978).

[60] *Id.* at 610, 617 and 619.

As is discussed at length on pages 18 through 26 of this brief, in fact, none of the usually valid assumptions identified by this Court as underlying this general decision to allow governmental deference to parental authority proves reliable in the case of parents forced to consider no-treatment decisions for their handicapped children. First, experience demonstrates that the "maturity, experience and capacity for judgment" normally anticipated from parents is often absent in these decisions, as parents, deprived of pertinent information, are forced, during a period of psychological crisis, to make hurried decisions to acquiesce in sociological judgments presented to parents as the "recommendation" of a significant number of health care providers trusted by the parent to "heal" and "save life." Second, the "natural bonds of affection" which normally lead parents to act in the best interests of their children have usually not yet formed with respect to the handicapped infant. Third, the introduction of sociological judgments by physicians distorts the normal role of parental decision-making in a context of *bona fide* medical uncertainty. Here, physicians ask parents to abandon their natural role as protectors of their children and undertake to decide between life and death. Instead of the neutral fact-finder envisioned in *Parham*, the physician may well be the architect of the problem rather than a contributor to its solution. Finally, the assumptions in *Parham* based on concerns about the future environment of the child and the protection afforded by subsequent professional review or intervention by family and friends prove illusory where the life of the child is forfeit.[61] In the instant case, both "experience and reality" overwhelmingly demonstrate the unreliability of the assumption that parents (or physicians acting through parents) will act in the "best interests" of the infant.

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[61] *Cf. The Guardianship of Becker*, 188 California Reporter, 781 (App. 1983); Herr, *The Philip Becker Case Resolved: A Chance for Habilitation*, 22 Mental Retardation 30 (1984).

While the Constitutional standard for required governmental action is not at issue in the instant case, the inapplicability of these basic assumptions to decisions to withhold treatment from handicapped children provides support both to the intent of Congress to regulate such treatment decisions within the framework of Section 504 and to the Secretary's consistent construction of the statute to authorize such regulation. This Court concluded in *Prince* v. *Massachusetts*, 321 U.S. 158 (1944) that "[P]arents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances to make martyrs of their children . . . ." *Id.* at 170. Congress and the Secretary surely may conclude that physicians and other health care providers are similarly barred from making martyrs of infants because of their handicap.

III. THE LANGUAGE OF BOTH SECTION 504 AND ITS 1977 IMPLEMENTING REGULATION CLEARLY PROHIBIT NO-TREATMENT DECISIONS MADE ON THE BASIS OF HANDICAP.

The plain language of Section 504 prohibits the denial of the benefits of any Federally assisted program to any person solely on the basis of that person's handicap. The legislative history of the statute demonstrates the intent of Congress to reach all aspects of discrimination against handicapped children and adults which occur in the provision of medical and treatment, including the "unexplained deaths" referred to by Congressman Vanik.[62] The "legislative heritage" of Section 504 as a civil rights statute, which, as understood by both the Legislative and Executive Branches, adopted the analogy of handicap to race and prohibited the use of handicap as the sole ground to differentiate between individuals, is set forth compellingly in Judge Winter's dissenting opinion below.[63]

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[62] 117 Cong. Rec. at 45974.

[63] *United States* v. *University Hospital, State University of New York at Stony Brook*, 729 F.2d 144, 162-63 (2d Cir. 1984) (Winter, J., dissenting).

The 1977 Departmental Regulation implementing Section 504, 45 C.F.R. 84, defines a qualified handicapped person, in the context of health care, to be one who meets the essential eligibility requirements for the service—i.e., need for particular beneficial medical treatment and care —and has, since 1977, prohibited disparate treatment of handicapped infants and their parents within such programs except as necessary to ensure that the services are equally effective.[64] Moreover, the regulation has required that such programs avoid any methods of administration, that would defeat or impair the objective of the treatment program i.e., improved health and welfare of the patient.[65] Last year, again with the strong involvement of numerous national parent organizations, Congress acted to clearly define the withholding of medically indicated treatment for a handicapped infant (under most circumstances) as medical neglect.[66] Certainly, medical neglect is harm. To the extent that it occurs on the basis of handicap in a program receiving Federal financial assistance, it is the type of harm based on discrimination which is prohibited by Section 504.

Amici, as parents of both handicapped and non-handicapped children, are well aware of the fact that those who operate hospitals or other health care facilities would never tolerate withholding essential services from non-handicapped children. Indeed, absent the bias directed against handicapped persons, no one would suggest that it would be appropriate to do so for *anyone*. Thus, if handicapped children were treated like non-handicapped children, beneficial medical services would never be withheld. As the legislative history of the statute clearly reveals, if Congress intended to prohibit anything under Section 504, it intended to forbid intentional harm di-

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[64] 45 C.F.R. 84.3(k)(4), 84.4(b)(1)(iv).

[65] 45 C.F.R. 84.4(b)(4).

[66] *See* Brief of *Amici Curiae* Orrin G. Hatch and Austin J. Murphy.

rected against handicapped children solely on the basis of their handicap by physicians and hospitals receiving Federal funds.

Thousands of parents of handicapped children led the hard-fought and long-pursued struggle to secure through the passage of Section 504 of the Rehabilitation Act of 1973 a statutory assertion of the equal value which must be afforded to the life of each handicapped child. A decision by this Court that Section 504 does not reach handicapped infants at risk of death because of decisions to withhold treatment made on the basis of their handicap would deprive handicapped children and their parents, in Judge Winter's words, "of a fairly won political victory" and expose them "to the possibility of future decisions excluding other services from Section 504."[67] If, as this Court has concluded in *Cleburne*, Section 504 belies the historical antipathy and prejudice toward mentally retarded and other disabled persons,[68] then surely, it must protect their lives from sociological judgments made by biased health care providers and paid for from the Federal treasury.

CONCLUSION

For the reasons set forth above, Amici urge this Court to reverse the judgment of the Court of Appeals for the Second Circuit.

Respectfully submitted,

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[67] *See supra* note 63.

[68] *Cleburne*, 105 S.Ct. at 3256.

APPENDICES

APPENDIX A

CANADIAN PSYCHIATRIC ASSOCIATION
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THE CANADIAN PSYCHIATRIC ASSOCIATION

POSITION PAPER

ON WITHHOLDING TREATMENT

2a

ON WITHHOLDING TREATMENT

A Working Paper

for

The Professional Standards and Practice Council

of

The Canadian Psychiatric Association

prepared by
M. N. Beck, M.D.
May 1978

This paper will offer a brief overview of the argument against the practice of withholding medical treatment from newborn retarded children.

The ethical issues stemming from this practice are most pointedly drawn by withholding repair of atresia of the duodenum in infants with Down's syndrome—"an easily correctible lesion" (1).

Similar principles are involved, but with more complex factors to be evaluated in terms of diagnosis and prognosis in cases of meningomyelocoele.

The Present Scene

In considering this practice we do not discuss a theoretical issue, but we deal with facts in clinical medicine in Canada today.

50 children with Down's syndrome and duodenal atresia were attended at the Sick Children's Hospital in Toronto over twenty years, of these, 27 were allowed to die (2).

This increasingly common act in medical practice is being vigorously promoted by able and influential advocates within our profession and within our society at large.

Withholding treatment from mongoloid children was first openly advocated as a valid option to Canadian medicine by Frank Guttman, M.D., F.R.C.S. in his article "On Withholding Treatment" in the Canadian Medical Association Journal of September 21, 1974 (1). Since then this topic has been subject to much discussion in the correspondence section of this Journal (3, 4).

Cooperman discussing meningomyelocoele in an editorial in the C.M.A.J. favors withholding treatment (5). In the New England Journal of Medicine April 1976 John Lachs, Ph.D. discussing the same topic commented, "the system if rightly conceived would not condone murder,

for those humanely put to death would not be human beings, only human forms" (6). In this he follows the philosophical position taken by the well known American theologian Joseph Fletcher (7, 8).

This practice has found professional support from such distinguished Canadian physicians as Dr. Clinton Stephens, Chief of General Surgery, Hospital for Sick Children, Toronto (9) and Dr. Colin Ferguson, Surgeon in Chief, Children's Hospital, Winnipeg (10) in their statements in the public media.

Individual instances of this practice have received wide coverage in the Canadian press (11, 12) and such reputable newspapers as the Montreal Gazette have given this practice editorial endorsement.

Battles both to permit and to enjoin this practice have been fought in Canadian and American Courts of Law (13, 14, 15).

The church is also involved. Withholding treatment was eloquently advocated in the report of the Anglican Task Force on Human Life prepared for consideration by the National Synod of the Anglican Church in Canada in August of 1977. This Task Force was headed by Dr. Lawrence Whytehead, a surgeon from Winnipeg, and had in its membership others from the medical and nursing professions. The report of this Task Force was just as eloquently condemned by the statements issued in response to it by the Canadian Association for the Mentally Retarded and other groups (16, 17).

The Professional Identity of the Physician

We recognize that many have advanced arguments for the withholding of treatment which are cogent both to themselves and to others. But we must ask, "is this the task of the physician?"

The aspiration of our profession has always been to spare no effort in our attempt to prevent illness, to promote healing, to reduce suffering and to save life.

The time-honored ethic of medicine, that a live patient is better off than a dead one and that a well person is better off than a sick one, is a simple ethic . . . but it has been an effective one.

Medicine is the healing profession. Medicine is the treating profession. Medicine has earned its honored position not only by appearing to take the patient's side, but by taking the patient's side in point of fact. We have become trusted because we deserve to be trusted.

Medicine betrays its identity, and fails in its public trust, when it finds any reason to dicker with death—when it accepts the death of an individual as a means of solving the problems of either the family or of society.

In this context using terms such as "ordinary means of treatment" and extraordinary means of treatment" is irrelevant. These concepts are outside that range of attitudes which the physician can adopt without running the risk of becoming an agent of harm to his patient.

The physician must be on the side of his patient. This is his traditional role, this is his moral role, and this is his only role.

The Clinical Reality

Psychiatrists have had the privilege to become those physicians most closely acquainted with that warm hearted, effervescent, usually happy, and warmly responsive group of people our society usually calls "mongoloids." They have taught us much about the appreciation of life, and they have shown us by their example the virtue and the value of an open human spirit.

We have also become familiar in our practices with the burden that can be placed on the family by retarded

children. However; experienced child psychiatrists will agree that the person afflicted with Childhood Schizophrenia, a disease more difficult to diagnose than Down's syndrome, causes more personal distress to the patient and suffering in his family (to say nothing of frustration and despair to medical people) than do mongoloid children or children with meningomyelocoele.

We would not decry all suffering, confuse it with illness or use it to justify less than the best of medical care. Suffering, like death, is a part of life. While it is terrible to bring it about unnecessarily, people often act nobly in accepting it, and through suffering their life has been enriched (18).

The members of this Association, parents, family members and others who have lived and worked closely with the retarded and their families also know the power of retarded children to strengthen and to revitalize their family units.

Whether the family unit becomes stronger or weaker depends upon those with whom they interact, as well as upon the retarded persons themselves. Neither human frailty, nor the ability to inflict suffering on others, is limited to intellectually subnormal individuals.

The Psychiatric Scene Today

During the professional lifetimes of many of our members, we have participated in a remarkable, even astounding, series of advances in the treatment of disorders of the mind. We ought to no longer assume that disorders of the mind are incurable, irreversible or always attended by much suffering.

In the thirties we saw a substantial reduction in our mental hospital population by the successful treatment of the psychotic illnesses caused by nutritional deficiencies.

In the forties we took part in the virtual elimination of General Paresis of the Insane. Till then patients with this disorder had occupied 5% of mental hospital beds.

In the forties and fifties we have seen the scourge of Manic-Depressive Psychosis become a highly treatable illness; first by the use of electro-shock therapy, then by the use of anti-depressant drugs, and more recently by the use of the simple salt lithium carbonate.

In the mid fifties the introduction of the major tranquilizers enabled us to obtain dramatic symptomatic improvement in the large number of our patients who suffer from schizophrenia.

During these same decades refinements of the techniques of psychotherapy brought about significant progress in the treatment of the psychoneuroses.

During the sixties we observed with delight the normal development of children born with phenylketoneuria and other inborn errors of metabolism which until then had invariably produced severe mental retardation. This advance was made possible by special diets. In the same decade because of improved surgical techniques we have watched large numbers of children growing up with intelligence in the normal range who would otherwise have been profoundly retarded because of hydrocephalus.

Of all times in history, this is not the one in which to be pessimistic about the possibility that still more major breakthroughs will be made in the treatment of mental disorders. The reasonable man now has good cause to anticipate the development of a biological method of treatment to correct or to modify the effect of the genetic defect which causes Down's syndrome.

These are not the times in which we should be either starting or expanding the practice of letting mongoloid infants die.

We also face this issue of withholding treatment at the very point in Canadian history when the efforts of voluntary associations like the Canadian Association for the Mentally Retarded and The Canadian Mental Health Association, along with the efforts of professional groups such as The Canadian Medical Association, The Canadian Paediatric Association and our own Association have succeeded in diminishing that oppressive social stigma which had been the lot of persons suffering from retardation and other handicaps. Working together we have also demonstrated that with good family care and with adequate education rehabilitation and therapy, that retarded people make an invaluable contribution to the depth and the texture of the matrix of our society.

"Conventional wisdom" can no longer adequately serve as the prognostic guide in any disorder of the mind. Prognosis in mental diseases involves the assessment of a complex interrelated set of genetic, biochemical, psychological, social and cultural factors in a world where new and major therapeutic breakthroughs in all these areas of study has become a regular occurrence.

The Philosophical Dilemma

The distinguished jurist of the State of Maine who found against withholding surgery in a brain damaged infant commented that, "the doctor's qualitative evaluation of the value of the life to be preserved is not legally within the scope of his expertise" (16). We agree. We would also accept as valid the parallel statement, "that philosophy has no special competence in moral decision making."

We are aware that the heat involved in this issue besetting medicine arises from confrontation between persons who advocate a system of ethics centered on the "sanctity of life" on the one hand, and persons who hold a system of ethics centered on "the quality of life" on the other hand.

These value orientations weigh upon physicians in a particularly unique way. Our moral judgments, whether they be right or wrong, can exert undue influence on others because of our social role; and also because we are interacting with the members of the infant's family at a time when their lives are in acute crisis.

Sweating from the heat of this philosophical and ethical confrontation, we find helpful direction from our awareness that there is a profound distinction between maintaining life and prolonging death. Physicians can determine when death is inevitable with reasonable certainty. Merely postponing the time of death has never been accepted as good medical practice.

Our profession had incorporated this principle into its definition of good medical care long before the much heralded advances in bio-medical technology of the last few decades—which advances are now erroneously proposed as the reason for our having to rethink our ethics on the issue being discussed in this paper.

We recognize the logic in the sentiment expressed by Freeman that it is time that society, and medicine, stopped perpetuating the fiction that withholding treatment from those who will thereby continue to live, is ethically different from terminating life.

We are also uncomfortably aware that it is all too easy to slip into "doublethink" in this complex area of moral decision making as we exercise our medical responsibility. Our minds can easily move from the goodly desire (held we hope by all physicians) for a rich, full and satisfying life for everyone; to the recognition that, as we perceive their present situation to be, these children may never enjoy such a life; to the latter becoming the reason for our countenancing or even inducing their death.

The role of medicine is to help make the quality of life the best possible for all; rather than to cut short the life

of humans with various defects—regardless of the degree or type of their deficiency.

Finally, we recognize that the protection of, and provision for, the welfare of the handicapped is a highly significant yardstick of the quality of our civilization; and that as stated by Dr. David J. Roy, "when we stand before a broken child and ask what we should do or avoid doing, we also stand before ourselves and before the civilization we both reflect and shape."

Recommendations

We therefore recommend:

1. That the Canadian Psychiatric Association oppose the practice of physicians withholding treatment of any kind, from retarded persons, which would not be withheld from persons with normal intelligence.

2. That physicians constantly strive to preserve life. And that when the medical reality of merely prolonging the process of dying is not involved, that withholding treatment be considered a legal and not a medical act; and that it be carried out—if at all—only under court order.

3. That the Canadian Psychiatric Association recognizes that the parents involved in these very difficult decisions need sympathetic and understanding assistance from experts in medicine, law, ethics, and clerical counselling; and that in a unique way it is the responsibility of physicians, and especially of psychiatrists, to see to it that the parents and family are fully informed.

4. That the Canadian Psychiatric Association advise the Canadian Medical Association and relevant specialty associations of our position on this matter.

(1) Guttman, F.M.; On Withholding Treatment, C.M.A.J.: 111, 520, 1974

(2) Girvan, D.P. and Stephens C.A.; Congenital Intrinsic Duodenal Obstruction, A Twenty Year Review of Its Surgical Management and Consequences; Journal of Paediatric Surgery, 9: 837; 1974

(3) DeVeber, L.L.; On Withholding Treatment; C.M.A.J. 111, 1183, 1974

(4) Baunemann, H.; Life Devoid of Value; C.M.A.J. 115, 1086, 1976

(5) Cooperman, E.M.; Meningomyelocoele: To Treat or Not to Treat; C.M.A.J.: 116, 1339, 1977

(6) Lachs, J.; Human Treatment and The Treatment of Humans; N. Engl. J. Med., 294, 839, 1976

(7) Fletcher J.; Ethical Aspects of Genetic Controls: Designed Genetic Changes in Man; N. Engl. J. of Med. 285, 776, 1971

(8) Fletcher J.; The Right To Die: A Theologian Comments; The Atlantic Monthly, 221 (April 1968), 63-64

(8)(a) Fletcher J.; Indicators of Humanhood: A Tentative Profile of Man; The Hastings Center Report; 2, 1, 1972

(9) Toronto Globe and Mail; Brain Damaged Baby Denied Operation That May Have Averted Starvation Death; October 8, 1974

(10) Toronto Star; Doctor Wants Life or Death Guidelines for Mongoloid Children: July 19, 1972

(11) Montreal Gazette; "Unless" Baby Allowed to Die; October 5, 1974

(12) Edmonton Journal; Stop Letting Helpless Babies Die; November 11, 1974

(13) Toronto Star; Christmas Eve Court Saves Baby; January 21, 1977

(14) Family Court Hearing; Judge M. Geness; London, Ontario, December 24, 1976

(15) Manie Medical Center Houle—Civ. Act No. 74-145. Superior Court, Cumberland, Maine. (February 14, 1974)

(16) The Toronto Globe & Mail; Severely Retarded Babies Should be Killed, Anglican Report Suggests; July 27, 1977

(17) Report of The Task Force on Human Life of the Anglican Church of Canada to General Synod; Editors, Whytehead L. and Clicdwick F; Considerations Considerations Concerning the Transit from Life to Death; Winnipeg, Man., May 1977

(18) Weber, L.J.; Who Shall Life; The Dilemma of Severely Handicapped Children and Its Meaning for Other Moral Issues; New York, Paulist Press, 1976

APPENDIX B

Principles on Treatment of Handicapped Newborns

American Jewish Congress/Bishops' Committee for Pro-Life Activities

1. We agree on the sanctity of human life. Every newborn has the right to basic care: nurture, sustenance and relief from pain. In cases where parents are unable or unwilling to provide such care, our government should take all reasonable steps to do so.

2. Medical intervention is not required when such intervention is clearly futile and would do no more than briefly prolong the act of dying.

3. Handicaps, in and of themselves, do not justify withholding medical treatment when such treatment offers reasonable hope of benefit and does not impose excessive pain or other burdens on the patient.

4. When there is reasonable disagreement among medical experts concerning the risks and effectiveness of alternate treatments for a life-threatening condition, parents have the right and obligation to make conscientious and medically informed choices between alternate methods of treatment. Parents who must make such difficult choices should ask themselves what course of action seems most likely to promote their child's best interest.

5. Government ought not to intervene in medical decisions made by parents of handicapped children unless there is a preponderance of evidence that one or more of the foregoing principles is being violated.

6. Government in this country should lend its support to the continuing treatment and care of handicapped children so that parents can make decisions about treatment without undue financial pressure.

COMMENTARY ON "PRINCIPLES ON TREATMENT OF HANDICAPPED NEWBORNS"

Today's joint statement on treatment of handicapped newborns was developed at a discussion between the staffs of the National Conference of Catholic Bishops and the American Jewish Congress on May 24, 1984 and refined since then by further dialogue. Our agreement on six basic principles does not unambiguously reflect all the concerns of the Catholic or Jewish participants in this area, nor could any one statement reflect the full complexity of our respective traditions in this area, but it does represent a significant consensus on both medical ethics in general and the rights of citizens with disabilities in particular. We would like to comment briefly on each of the six principles in our statement.

(1) Respect for the inherent dignity of human life demands that basic sustenance and care be provided to handicapped infants, quite aside from medical intervention that may be necessary to correct a particular life-threatening condition. Our reference to government support for such care is intended to mean that the level of government with authority to act, whether local, state or federal, should assist handicapped children as it assists others in need.

(2) Treatment which can only briefly prolong the dying process is not morally obligatory. Taken together with (1), this corresponds to the Catholic teaching that "when inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted" (*Declaration on Euthanasia*, 1980). In dealing with dying patients, non-routine medical intervention aimed at prolonging life can also hasten the moment of death. Since Jewish teaching prohibits such hastening, parents facing such a dilemma have the right

in choosing medical treatment to choose the course of action that seems to them the most prudent.

(3) Treatment of handicapped newborns should respect the principle of non-discrimination. To use terms which are common in medical ethics: morally obligatory or "ordinary" means do not become optional or "extraordinary" merely because the patient is handicapped. Treatment decisions should take a handicap into account only when it substantially decreases the benefit or increases the burden of a particular treatment. A similar policy was expressed in a May 1982 directive for the U.S. Department of Health and Human Services, which said that an infant's handicap does not justify withholding life-sustaining treatment unless it renders that treatment "medically contraindicated."

(4) Medical procedures are rarely without risks. At times, parents must choose between alternate methods of treatment or no treatment at all. It is the right of parents to weigh risks and choose the course of action that seems to them to yield the proper risk/benefit ratio. Parental choices in such circumstances should be made in terms of what course of action will serve the child's best interest. What is best for the individual child should take precedence over any conflicting interests of parents or society. The expression "child's best interest" does not include the possibility of negative judgments about the value of handicapped children's lives.

We recognize that the phrase "best interest of the child" is not without ambiguity as a legislative standard, for the phrase could be misused to mask subjective judgments about the value of handicapped children's lives. A more complete analysis is needed to spell out the phrase "best interest" in objective terms—for example, by stating that parents should take the option that seems to have a reasonable chance of advancing the child's long-term survival—but this matter requires further study and discussion.

(5) Where parents are not denying basic care to their child, not discriminating on the basis of handicap, and not acting out of ignorance or lack of conscientious concern, their medical decisions should be respected by the law. But the appropriate agency of government should be able to investigate plausible claims that these principles have been violated; if it finds a preponderance of evidence for concluding that they have, it should act to protect the child. Our consensus statement does not discuss what the most appropriate mode of reporting or investigation might be in such cases, and does not specify a particular type of government intervention to protect children's rights.

(6) Parents often feel a pressure toward denying life-saving treatment to their handicapped children when they contemplate the cost of supportive services—or the lack of such services—for the child who survives. Increased local, state and federal assistance for these children and their families is an important ingredient in any complete solution to the problem of discrimination against handicapped newborns.

In conclusion we would like to express our satisfaction with the atmosphere of cooperation and mutual esteem in which this dialogue has been conducted. We rejoice in our common ground of concern regarding this serious contemporary problem and look forward to further discussions.

Rev. Edward M. Bryce
Director, Office of Pro-Life Activities
National Conference of Catholic Bishops

Dr. Michael Wyschogrod
Director, Institute of Jewish-Christian Relations
American Jewish Congress

July 25, 1985

APPENDIX C

Resolution Adopted by the Association for Retarded Citizens of the United States

May 1, 1982

WHEREAS, the Association for Retarded Citizens of the United States is gravely concerned that the practice of withholding medical treatment from persons—solely on one basis of a diagnosis or prognosis of mental retardation—is increasing in this country at an alarming rate;

THEREFORE BE IT RESOLVED, the Association for Retarded Citizens of the United States reaffirms the position it took in 1973 condemning such practices,

AND, FURTHERMORE, does *not* support the right of physicians to recommend *nor* the right of parents to agree to the withholding of medical treatment where the only basis for such a decision is the diagnosis or prognosis of mental retardation.

FURTHERMORE, it is the position of the Association for Retarded Citizens of the United States that counseling by a physician regarding the "quality of life" for an individual with mental retardation should never extend beyond the physician's *medical* knowledge of the condition.